

QUALITY OF LIFE AMONG YOUNGER WOMEN WITH BREAST CANCER

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CERTIFICATE

This is to certify that this dissertation on “**QUALITY OF LIFE AMONG YOUNGER WOMEN WITH BREAST CANCER**” is a bonafide work done by **Dr. Biswajit .D**, in the Department of Medical Oncology, College of Oncolgical Sciences, Adyar, Chennai, under my overall supervision and guidance, to my satisfaction

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INTRODUCTION

The diagnosis of breast cancer despite improved overall survival continues to generate fear and turmoil in the lives of women and their families. Prevalence studies of psychological distress indicate that one of every three newly diagnosed patients experiences significant difficulty in adjustment. [1] Further evidence suggests that the diagnosis of breast cancer generates more anxiety than any other cancer diagnosis. [2]

At the time of diagnosis patients experience uncertainty, confusion and distress. Psychological distress can be exacerbated by inadequate information, complex treatment decisions, and scheduling difficulties with various specialities. As treatment begins, concerns related to physical functioning, body image, mood, sexuality, family and vocational pursuits quickly emerge. Surgical options which include lumpectomy, mastectomy and reconstruction present unique issues as the patient contemplates the advantages and disadvantages of each procedure. Following surgery adjuvant therapy generates additional physiological assaults that further affect body image, sexuality and family life.

They require rehabilitative assistance beyond the physical domain. Major rehabilitation problem areas include physical, psychological, social, sexual, nutritional, financial and vocational ones.

For younger women the physical and psychosocial morbidity associated with treatments may affect their ability to successfully function in social roles that typify this age group. Hence we would like to study the quality of life issues in this subset.

AIMS

1. To describe the quality of life among breast cancer women with age less than or equal to 35 years at the time of diagnosis.
2. To determine the contribution of socio demographic, medical and psychosocial factors on quality of life.
3. To study the impact of breast conservation treatment and mastectomy on the quality of life.

REVIEW OF LITERATURE

Young breast cancer patients have an aggressive behavior with poor outcome .The patients are in their reproductive age group and are concerned with fertility issues. The literature pertaining to quality of life in this subset is limited.

Incidence of breast cancer

In India the incidence of breast cancer has steadily increased over the year's with 100000 new cases being diagnosed every year. At a given time there are as many as 1 million patients with breast cancer in India. The life time risk of developing breast cancer is 1:30 (incidence rate 20/100000) in urban India and 1:65 (Incidence rate: 8.6/100000) in rural India. ^[3]

Defining young breast cancer patient:

Of the three defining indicators , two of these- women having young children and

women who have not yet reached menopause are objective, the third being women of child bearing age which is subjective.^[4]

The carcinomas arising in women aged 35-44 years are not significantly different from those occurring in women aged 50-67 years. The carcinomas arising in women aged less than 35 yrs are clearly different. This emphasizes the importance of the subdivision of 50 years age group.^[5]

Trends in Breast cancer in younger women in contrast to older women

Incidence

According to data from the Surveillance, Epidemiology and End Results program (SEER) and the National centre for health statistics, the probability of developing breast cancer were less than 1% between the ages 20 and 29 and 6.5% between ages of 30 and 39. The absolute number of breast cancer nearly doubled in young women from 1970 to 1990 but the age adjusted breast cancer increased only slightly. In U.K., the incidence of breast cancer in the 20-24 year age group is 1.2 per 100000 and between 15-19 years of age the rate is 0.3 per 100000 women.^[6]

Clinical profile [7]

The breasts are physiologically more active resulting in cyclic nodularity making breast self examination and physical examination more difficult. Mammograms are

difficult to interpret owing to the density of the breast. A delay in diagnosis is more likely in young breast patients.

They present with large tumors and a five fold increase in inflammatory carcinoma in women less than 30 years relative to those over 50 years.

The various risk factors which were higher when compared to older women were first birth at late age, low parity, oral contraceptive pills, positive family history of breast cancer and atypical ductal hyperplasia. [8]

The hereditary breast cancer constitutes 36 % to 85% of patients diagnosed with breast cancer under the age of 30. A study by Ashutosh et al revealed that the incidence of a positive family history was similar to the general population with breast carcinoma.

Pathology

The relative incidences of medullary carcinoma and ductal carcinoma in situ are increased. Lobular and tubular cancers are decreased. They presented with higher tumor grade, positive lymph nodes, extensive intraductal component, lymphovascular invasion, major mononuclear cell reaction, and hormonal receptor negativity. [7]

Although c-erbB-2 expression has been related to poorer differentiation, there was no difference in expression between the different age groups. [5]

A greater percentage of tumors with S- phase fractions were correlated with

decreasing age. 80% of tumors from women of ages 30-35 had abnormal accumulation of mutant p53 protein. ^[9] Multivariate analysis confirmed that young age was a significant independent predictor of adverse outcome.

Management

The issue of local control in young women has been the subject of conflicting reports in literature. Mathew et al suggested that local control rates in young women are more a function of histopathology, biologic features than the surgical procedure performed. ^[10]

The incidence of chemotherapy induced ovarian failure is related to the drugs administered, total dose and age of the patient. Alkylating agents are more likely to induce ovarian failure. Older premenopausal women experience ovarian failure more than their younger counterparts. CMF resulted in amenorrhea in 50% of women under the age of 40 years and 93% over the age of 40. The data on total dose indicate that permanent amenorrhea occurs after a mean total dose of 9.3 grams of cyclophosphamide in less than 40 yrs versus 5.2 grams in patients over the age of 40. [11]

The risk of osteoporosis and cardiovascular disease is increased in a milieu of estrogen deprivation.

Because 50 % of the patients under the age of 40 years retain their ovarian function, pregnancy is an option. Limited scientific information is available. A small series of patients with breast conserving therapy and subsequent pregnancy were matched with women without pregnancy. No differences were noted for quality of life, local recurrences or survival. [7]

Survival patterns

Marie Swanson et al., in their study found that women in these younger age groups 20-29 and 30-39- constitute about 7% of white breast cancer patients and 14% of black breast cancer patients. They account for 9.7% and 17.2 % of deaths among white and black women respectively. [12]

There are various possible explanations for the poor survival experience of younger women with breast cancer.

1. High estrogen levels induce more rapid tumor growth rate.
2. Poor prognostic factors that reduce survival as discussed earlier.
3. Higher mortality from breast cancer in part due to the lack of competing causes of death.
4. Biology of the disease which differs significantly among the younger women in contrast to women in their 50s or older.^[12]

Young women's concerns and quality of life issues (4)

The diagnosis and treatment of breast cancer in a young woman is a major stress that is followed by significant psychological morbidity. There are a number of reasons why young women with breast cancer may experience increased psychosocial morbidity compared with older women. ^[4]

1. From a developmental perspective, they experience the stress of cancer concurrent to the multiple stressors associated with early stage of the family life cycle.
2. Global QOL assessed by Ladder of life suggests that problems associated with breast cancer continue to persist several years after diagnosis. Kroenke et al found that women less than 40 yrs of age experienced greater declines in physical roles, bodily pains, social functioning, and mental health compared with women without breast cancer. [13]
3. They may experience more disruption to self image and sexuality
4. They may have concerns about career, feeling unable to change jobs or fearing loss of a job.
5. They also experience premature menopause, resulting in a range of distressing physiological and psychological symptoms like vaginal dryness, hot flushes, dyspnoea, mood swings and short term memory loss. [4]
6. Fears about not surviving to see their children grow to adulthood, infertility and cancer recurrences. The meaning of having children is an important aspect of quality of life not only in terms of the experience of pregnancy, child birth

and mothering. The experience of breast cancer in young women includes anxiety, depression, fear and anger. The fear is more related to concerns as not living to see their children grow up rather than the anxiety of relapse. [4]

Impact of Quality of life on specific treatment. [14]

Mastectomy: The loss of self esteem associated with mastectomy causes anger, anxiety, fear and sadness. The durations of these symptoms may be prolonged

Lumpectomy: Breast conservation provides an alternative to mastectomy that lessens the effect on body image and self esteem. However some women may opt for mastectomy for the fear of recurrence. [15]

Reconstruction: Immediate or delayed reconstruction offers an opportunity to restore positive body image and to increase self esteem. An intact body enhances sexual functioning and satisfaction. [16]

Impact of breast – conserving treatment and mastectomy on the quality of life

In the treatment of early stage breast cancer, the issue of extensiveness of surgery has long been central. Rational decision making should be based on theory and empirical data with respect to three end points: [17]

1. Likelihood of local tumor control and survival.
2. The burden of the treatment experienced by the patients and its effect on

quality of life.

3. Costs of treatment.

Quality of life.

Meyerowitz et al had suggested a model for impact of breast cancer and its treatments on the patient. The main areas in this model include psychological discomfort, changes in life patterns, and fears and concerns. [18]

Psychological Discomfort

The three most commonly observed symptoms of psychological distress are depression, anxiety and anger. In 9 out of the 16 studies there was no difference in psychological distress between the different treatment modalities. 4 studies reported a difference in favor of breast- conserving group: general adjustment, pessimism, emotional adjustment, depression, emotional reactions. Two studies reported a difference in favor of the mastectomy group: depression anger, confusion, overall distress and psychological distress. [17]

With respect to psychological distress there is a current lack of solid proof of a more favorable psychological adjustment after breast conserving treatment. Conserving the breast does not alter the adjustment problems. They need as much counseling support as patients who undergo mastectomy. [19]

Changes in life patterns

It is measured in three areas: Physical functioning/ daily activities, sexual functioning and social adjustments. In seven of the twelve studies, no difference was found between the two treatment arms. In one study lymphedema was less and arm function was better after conservative treatment but in another the arm motion was better after mastectomy. [17] Levy et al reported less physical disability and less loss of appetite after mastectomy. [20]

Physical function and activity level are similar according to most investigations. There was no difference between treatment groups in the long run.

Sexual functioning was investigated in 11 studies. No difference was found in 7 studies. The differences found in the other studies were all in favor of breast conserving group. More dysfunction , later resumption of sexual activities, changes in breast stimulation, talking less openly about sexuality, and less satisfaction with sexual experiences were observed after mastectomy.[17]

Thus with regard to sexual functioning, it must be concluded that patients who

undergo a mastectomy have an increased chance of the problems in this respect.

Social adjustment was investigated in 11 studies. In six of these studies, no differences were found between the treatment groups. In two studies, the breast conserving treatment turned out to lead to better social support from friends, more marital affection and openness about feelings. However three other studies reported more conflicts, difficulties in planning, less cohesion, and social support in this group. [17]

The effect on the marital and social relations of patients remains unclear. [17]

Fears and concerns

12 of the 18 studies investigated aspects of body image after surgery. Of these, only 2 studies found no differences between treatments. In the 12 studies that found differences, a more positive outcome with respect to body image was found for the groups with breast – conserving treatment. These patients felt more attractive and less ashamed, anxious, embarrassed, or concerned about their bodies.

The fear of recurrences and death was investigated in 8 studies. In six of them, no differences were found between the treatment options. Two studies reported more fear of recurrence after mastectomy than after breast conserving treatment. [17]

Financial aspect

The length and costs of breast conserving treatment with the subsequent follow up schedule are higher. [17]

The impact of different surgical treatment modalities in the case of early breast cancer on quality of life shows few differences.

Adjuvant Chemotherapy

Alopecia, fatigue, hemorrhagic cystitis, myelosuppression, nausea and vomiting consistently affect the psychological well being; exacerbate the assaults on body image, sexual satisfaction and overall quality of life. [21, 22, 23]

Radiation therapy

The most frequently cited side effects are fatigue, which inhibits day to day functioning and thereby decreasing the quality of life. Patient also possesses significant concerns related to pain and the duration of treatment. [24, 25]

Psychosocial vulnerability

For breast cancer patient's survivorship begins on the day of diagnosis as women begin to redefine all aspects of their lives. Four primary points exist in the psychosocial care of cancer patients. [26]

1. Patient experience an “existential plight” during the first 3 months after their diagnosis.[27]
2. If a remission occurs, patients begin to live with cancer. They incorporate disruptions of daily life into their routines.
3. The fear of recurrence complicates the psychosocial course. Patients gain critical information and knowledge concerning their disease and treatments. They form supportive relationships with health care teams and other patients.
4. When the treatment fails, terminal illness and the potential threat of abandonment confronts.

Since the patients vary significantly in their ability to adapt to their cancer diagnosis and treatment, there are defined variables which promote adaptation.

Table 1. Variables associated with psychosocial adaptation. ^[28]

Social support

Marital status

Living arrangements

Number of family members and relatives in vicinity

History

Substance abuse

Depression

Mental health

Major illness

Current concerns

Health

Religion

Work- finance

Family

Friends

Self appraisal

Others

Education

Employment

Physical symptoms

Sexuality and body image. [29]

A diagnosis of breast cancer in younger women has the greater potential impact of the cancer therapy on her reproductive life.

1. Mastectomy versus breast conservation A number of studies have compared quality of life in women who had modified radical mastectomies or breast conserving surgery. Psychosocial adjustment, whether measured in terms of major psychiatric disorders or general levels of emotional distress, does not differ between treatment groups. Marital satisfaction or divorce rates also are quite similar in both the groups. Questions about body image demonstrate that women with less extensive surgery feel more attractive and sexually desirable [30,31]. Pozo and colleagues noted that younger women were the most distressed patients in both the mastectomy and breast conserving groups when compared to older women.[29]

2. Breast reconstruction.

The sexual function and body image are more positive after breast reconstruction. The impact of breast reconstruction on sexual frequency and satisfaction is less clear. [29]

3. Systemic therapy and sexuality.

Chemotherapy was related to greater sexual problems after surgery and continued beyond the first year of treatment. Ganz et al found that sexual functioning was most impaired for women no longer menstruating after chemotherapy. [32]

The clinical symptoms of premature menopause include sudden onset of hot flashes, vaginal dryness, and atrophy, Dyspareunia. Post menopausal vaginal atrophy is associated with recurrent urinary tract infections or vaginal monilial infections. [33] The alopecia, weight gain and pallor often associated with chemotherapy can temporarily make women feel unattractive. One other hormonal change that may occur is a decrease in circulating androgens. About 50 % of the circulating androgens are of ovarian origin while the rest are produced by the adrenals .It may interfere with a woman's desire and arousability. [34]

The onset of vaginal dryness from abrupt menopause is the important factor affecting sexual functioning. The long term impact of chemotherapy on sexual functioning is thus related to its impact on ovarian functioning.

Younger women whose ovarian function returns after chemotherapy and women

already postmenopausal may show only short term effects. Those women whose ovarian function is severely affected may show long term effects.^[32,35]

The prevalence of hot flashes, difficulty with bladder control, vaginal dryness and stiffness and soreness were all higher in community based cohorts of women such as SWAN and the Melbourne Women's Midlife Health project.^[36]

Fornander and colleagues suggested that Tamoxifen decreases sex hormone-binding globulins with net increase in the bioavailability of androgens. It also prevents vaginal atrophy.^[37]

Understanding specific aspects of sexual problems that affect younger women and extend over time is relevant for oncologists. Vaginal rings, a form of estrogen that dispenses low doses of estrogen with little systemic absorption and lubricants may prove beneficial. Although sexual functioning is an important quality of life issue for women, it may be difficult for patients to initiate discussion and the clinicians should routinely raise the topic. Interventions to help women feel more sexually attractive may be beneficial, especially among women for whom these feelings were altered as a result of treatment or surgery.^[32]

Spirituality

One salient aspect of the distress of life threatening or terminal illness is spirituality. Smith and colleagues found that a higher level of spirituality is associated with an increase in the patient's ability to normalize death. In the study of 116 adult medical oncology outpatients, a significant negative relationship was found between the interaction of spiritual awareness with the patient's personal death perspective and psychosocial distress.^[38]

Effects on Interpersonal and Family Relations. [39]

When breast cancer occurs in young women, the demands on family life are heightened as family members cope simultaneously with day to day care of the children, careers, with the added worries of a life threatening diagnosis, surgery, and the toxic effects of chemotherapy.

1. Emotional impact

Younger women experience more emotional distress. They sought professional help more often and perceived mastectomy as having more negative influence on their sexual relationships than older women. They had significantly poorer mental health and a lower sense of well being

2. Emotional impact on spouses

Husbands of breast cancer patients have reported psychosomatic problems such as

eating disorders and sleep disturbances, distress levels comparable to the levels reported by their wives, and feelings of heightened anxiety and depression, starting at the time of diagnosis and continuing through the first year of surgery.

3. Impact of breast cancer on children

The limited research in this area indicates that children like their parents, are not immune to the stressful effects of the illness. The adjustment levels of the children were affected by the marital adjustments of the parents and by the quality of the parent- child relationship

4. Impact of breast cancer on Marital Relationship.

Licthman et al studied the marital adjustment of breast cancer patients and found that the quality of relationship stayed the same or improved after the mastectomy. Only 7% of the couples divorced .Younger couples reported higher marital satisfaction than the older couples. Only one fourth to one third of couples experience difficulties in sexual problems. Many women with advanced breast cancer were able to discuss their illness with their family members [40].

Cognitive –Behavioral Interventions.

Patients frequently manifest a variety of symptoms as direct effects of cancer and

its treatment. Most commonly identified symptoms include acute and chronic pain, anxiety, insomnia, hypochondrias is, anticipatory nausea and vomiting. A variety of cognitive and behavioral interventions can systematically be administered. [14]

Survivorship

A number of studies indicate that while cancer survival may be achieved, it is still a disease that can substantially affect several physical and psychological aspects of a survivor's life. Hyper vigilance and hypochondriasis are common reactions. [41] They experience challenges in four critical life domains. 1. Physical health, 2Psychological and social well being, 3.Maintaining adequate health insurance and 4. Employment. [42]

Physical health challenges include fear of recurrence, the possibility of second malignancy and other late effects of aggressive treatment. Many survivors actively meet these challenges through preventive regimes of diet, exercise, stress reduction and smoking cessation. In general most survivors report mild to moderate psychological distress. Cancer survivors often may be threatened with policy cancellations or reduction in coverage. [14]

Employment issues include failure to be promoted, negative attitude toward cancer and undue criticism from supervisors or co workers.

One of the most important variables consistently related to QOL was the number of days of work or usual activity missed in the 3 months after diagnosis. Those who reported missing all 3 months had lower quality of life on all domains. This measure is possibly associated with depression at the time of diagnosis. [14]

Qualities of life in long term, disease free survivors of breast cancer.

Deborah et al studied the quality of life of 5-10 year breast cancer survivors and found that the presence of symptoms at the time of survey and use of chemotherapy after diagnosis to be the strongest correlates of QOL. The Stage at diagnosis, age at survey, recurrence since diagnosis, and number of years since diagnosis did not highly correlate with QOL. [43]

Women who did not receive chemotherapy or hormonal therapy had higher QOL than women who received either type of therapy. Long-term consequences of adjuvant therapy may be particularly pronounced in terms of sexual issues. [43]

The findings from a large longitudinal study of QOL among long-term survivors across a broader age distribution, suggest that the effects of adjuvant therapy persist many years after the completion of chemotherapy. [44]

The presence of inadequately managed breast cancer related pain, and other cancer-related symptoms, many years after diagnosis may have a significant impact on the day-to-day well-being of younger survivors. [43]

A study among 8 year survivors of a consecutive series of women with breast

cancer showed that the quality of life of survivors who remained free of disease during the entire follow up period was similar to that among women who had never confronted cancer. Two exceptions where survivors experienced poorer quality of life were more frequent arm problems and less satisfaction with sexual life.^[45]

Conclusion

Patient and families have very personal perceptions of breast cancer and treatments that are influenced and developed over time as a result of many factors. Information and education must be consistently available as patients and families move across the disease continuum from diagnosis to treatment to recovery. Comprehensive Psychosocial assessment should also include intimacy, sexuality and spirituality. Undetected and untreated psychological distress can jeopardize treatment outcome, stimulate dissatisfaction with care, and increase overall health care costs.

Menopausal symptoms and problems with relationship, sexual functioning, and body image might explain why younger women have greater psychological morbidity. Preparing younger women for the impact of breast cancer and helping women deal with problems may improve their quality of life. Younger breast cancer survivors may be in need of interventions that specifically target these issues. Clinicians should monitor how

women respond to their diagnosis in terms of stopping work or their usual activity. Women who stop working or their usual activity are at significantly greater risk for impaired quality of life in all domains and should be targeted for intervention.

PATIENTS AND METHODS

Younger Women diagnosed as breast cancer at Cancer Institute (WIA), who underwent the Institute's protocol treatment from 1994-2005 were included for the study.

Inclusion criteria

1. Age less than or equal to 35 years.
2. Patients with TNM stage I, II and III.
3. Patients who have completed 18 months of follow up.

Exclusion criteria

1. Patients with metastatic disease
2. Patients with histopathological diagnosis of Sarcomas and Lymphomas

Methods

Sample

The medical records of 100 patients who met the inclusion criteria from 1994-2005 were reviewed and included in the study. Women were then contacted on phone or letter to review at the breast cancer clinic where the quality of life questionnaire was administered after taking informed consent. Out of the patients who had been contacted 51% of them responded.

Treatment

Depending on the stage of the disease, patients had received neo-adjuvant chemotherapy and hormonal therapy as per the institute protocol.

Questionnaire

Sociodemographic variables included age at diagnosis, marital status, level of education and employment status. Medical variables included cancer stage, type of surgery, hormonal status, menopausal status, ovarian function and child birth after diagnosis.

Quality of life

The quality of life issues were studied using the EORTC module QLQ –C30 and the BR 23 Questionnaire. The questionnaire has been validated on Indian patients. [46]

EORTC QLQ C 30 and BR 23

The EORTC module QLQ-C30 is a 30 item questionnaire composed of 5 multi item functional subscales : Physical health , role function, emotional function, cognitive function and social functioning; 3 multi item symptom scales measuring fatigue, pain and emesis; a global health subscale and 6 items to assess financial impact and general symptoms .

The BR-23 module evaluates treatment – related symptoms of breast cancer. It incorporates 3 functional scales (body image, future perspectives and sexuality) and 4 symptom scales (arm symptoms, breast symptoms, hair loss and side effects of systemic therapy). In addition to this, a few other issues related to sexual dysfunction and menopausal symptom were also assessed

The questionnaires were available in 4 languages namely English, Tamil, Telugu and Malayalam which were administered according to the patient's vernacular languages. Patients completed their questionnaire on their own; however some of them required assistance.

Statistical Analysis.

Scoring of the QLQ – C30 and BR-23 was done according to the procedures described in the EORTC manual.

Descriptive and inferential statistics were used in order to analyze the data using SPSS version 13.

RESULTS

Table 1 Age at Diagnosis

Age(years)	N=51(%)
21-25	7 (13.7)
26-30	27 (52.9)
31-35	17 (33.4)

Table 2 Educational status

	N=51
Primary	27 (52.9)
Secondary	17 (33.33)
Graduate	6 (11.8)
Postgraduate	1 (2)

Table 3 Occupation before and after diagnosis of cancer

Occupation	After		
Before	Housewife	labourers	professional
Housewife	37	2	0

Labourers	1	10	0
Professional	1	0	0

Table 4 Marital status before and after diagnosis of cancer

Marital status	After			
Before	Married	Divorced	widow	single
Married	42	2	2	0
Single	4	0	0	1

Table 5 Stage and Treatment

Characteristics	No of patients
Stage	
I	2 (3.9)
II	31 (60.8)
III	18 (35.3)
Type of surgery	
MRM	33 (64.7)
BCS	18 (35.3)
Chemotherapy	51 (100)
Type of chemotherapy	
CMF	32 (62.7)
FAC	16 (31.4)
FEC	3 (5.9)
Radiotherapy	51 (100)

*MRM- modified radical mastectomy, BCS-Breast conservation surgery,

CMF-Cyclophosphamide, Methotrexate, 5-Fluorouracil

FAC-5-Fluorouracil, Adriamycin, Cyclophosphamide.

FEC-5-Fluorouracil, Epirubicin, Cyclophosphamide.

Table 6 Hormonal manipulation

Characteristics	No of patients	%
Hormone therapy	42	82.4
BSO	22	43.1
Radiocastration	4	7.8
Chemo induced amenorrhea	9	17.6

Table 7 Sexual and menopausal symptoms

Symptoms	N=51 (%)
Hot flashes	16 (31.4)
Vaginal dryness	7 (13.7)
Vaginal discharge	11 (21.6)
Dysparuenia	11 (21.6)
Normal menstrual cycles	22 (43.1)

Table 8 Sexual function and Hormonal Therapy

Item scale	Hormonal	N	Mean	SD	sig
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	therapy		scores		
Sexual functioning	yes	29	67.57	35.48	0.01
	no	22	33.44	33.31	
Sexual enjoyment	yes	29	64.28	37.16	0.013
	no	22	29.55	35.16	

Table 9 Quality of life (Functional Scales)

Item scale	Mean scores	SD
Physical functioning	86.39	17.56
Role functioning	87.01	22.67
Emotional Functioning	82.11	23.20
Cognitive functioning	89.25	19.81
Social functioning	87.7	24.6
Body image	80.44	28.63
Sexual functioning	61.54	37.18
Sexual enjoyment	58.15	38.84
Future perspective	72.62	33.81

Table 10 Quality of life (Symptom Scales)

Item scale	Mean scores	SD
Global health status	77.93	20.74
Fatigue	18.10	22.1
Pain	19.60	26.64
Insomnia	8.49	25.68
Appetite loss	5.88	17.30
Breast symptoms	8.98	14.51
Arm symptoms	15.52	20.35
Systemic side effects	13.04	11.93
Financial difficulties	40.5	39.67

Table 11 Impact of MRM and BCS on Quality of life. (Functional scale)

Item scale	Therapy	N	Mean scores	SD	Sig
Physical functioning	MRM	33	87.81	17.32	0.43
	BCS	18	83.77	18.18	
Role functioning	MRM	33	89	21.44	0.40
	BCS	18	83.38	24.98	
Emotional Functioning	MRM	33	83.68	22.86	0.52
	BCS	18	79.25	24.21	
Cognitive functioning	MRM	33	89.51	17	0.90
	BCS	18	88.77	24.69	
Social functioning	MRM	33	87.96	26.02	0.91
	BCS	18	87.22	22.44	
Body image	MRM	33	82.38	26.2	0.51
	BCS	18	76.88	33.03	
Sexual functioning	MRM	33	70.33	34.51	0.02
	BCS	18	45.44	37.41	
Sexual enjoyment	MRM	33	69.72	35.75	0.003
	BCS	18	36.94	36.00	
Future perspective	MRM	33	71.81	31.33	0.82
	BCS	18	74.11	38.75	

Table 12 Impact of MRM and BCS on Quality of life (symptom scale)

Item scale	Therapy	N	Mean scores	SD	sig
Global	MRM	33	82.31	18.01	0.04
	BCS	18	69.90	23.42	
fatigue	MRM	33	18.07	21.25	0.98
	BCS	18	18.16	24.42	
Pain	MRM	33	17.65	25.02	0.49
	BCS	18	23.14	29.82	

Insomnia	MRM	33	8.06	25.02	0.87
	BCS	18	9.27	27.58	
Appetite loss	MRM	33	8.06	17.62	0.92
	BCS	18	5.55	17.18	
Breast sym	MRM	33	9.84	16.19	0.571
	BCS	18	7.40	11.02	
Arm sym	MRM	33	10.91	17.73	0.027
	BCS	18	23.98	22.58	
Systemic side effects	MRM	33	12.28	10.59	0.54
	BCS	18	14.49	14.3	
Financial difficulties	MRM	33	38.36	36.51	0.60
	BCS	18	44.44	45.26	

Table 13 Impact of Ovarian function on Quality of life

Item scale	Therapy	N	Mean scores	SD	sig
Global functioning	Ablated	29	78.44	21.07	0.84
	Preserved	22	77.26	20.26	
Physical functioning	Ablated	29	85.96	19.04	0.84
	Preserved	22	86.95	15.81	
Emotional Functioning	Ablated	29	78.77	25.55	0.24
	Preserved	22	86.51	19.37	
Cognitive functioning	Ablated	29	92.31	13.59	0.20
	Preserved	22	85.22	25.65	
Social functioning	Ablated	29	85.75	27.32	0.52
	Preserved	22	90.27	20.89	
Body image	Ablated	29	77.60	30.42	0.42
	Preserved	22	84.18	26.32	
Arm symptoms	Preserved	29	12.1	19.26	0.174
	Ablated	22	19.9	21.33	

Sexual functioning	Ablated	29	70.24	35.75	0.05
	Preserved	22	50.09	36.88	
Sexual enjoyment	Ablated	29	71.27	35.38	0.004
	Preserved	22	40.86	37	
Future perspective	Ablated	29	70.17	36.04	0.551
	Preserved	22	75.86	31.15	

Table 14 Impact of survival duration on quality of life

Item scale	Therapy	N	Mean scores	SD	Sig
Global functioning	<=5yrs	33	79.53	20.53	0.46
	>6yrs	18	74.99	21.39	
Physical functioning	<=5yrs	33	87.42	17.18	0.57
	>6yrs	18	84.5	18.57	
Emotional Functioning	<=5yrs	33	84.92	20.10	0.34
	>6yrs	18	77.88	28.16	
Cognitive functioning	<=5yrs	33	88.66	22.17	0.77
	>6yrs	18	90.33	15.07	
Social functioning	<=5yrs	33	90	19.86	0.37
	>6yrs	18	83.5	31.81	
Body image	<=5yrs	33	82.14	26.91	0.57
	>6yrs	18	77.32	32.13	
Sexual functioning	<=5yrs	33	60.66	37.68	0.82
	>6yrs	18	63.16	37.27	
Sexual enjoyment	<=5yrs	33	55.51	37.96	0.51
	>6yrs	18	63	41.08	
Future perspective	<=5yrs	33	72.78	32.79	0.96
	>6yrs	18	72.33	36.58	
Arm symptoms	<=5yrs	33	7.06	9.79	0.20
	>6yrs	18	12.49	20.46	
Breast symptoms	<=5yrs	33	15.34	20.0	0.93
	>6yrs	18	15.87	21.58	

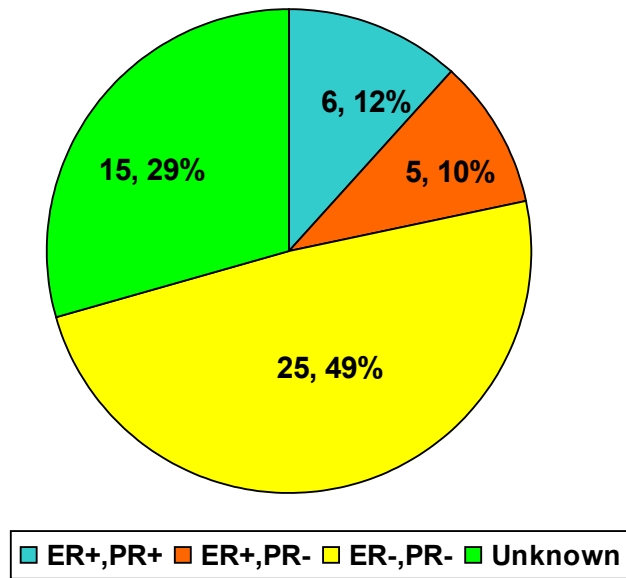


Figure 1. Hormonal Receptor Status

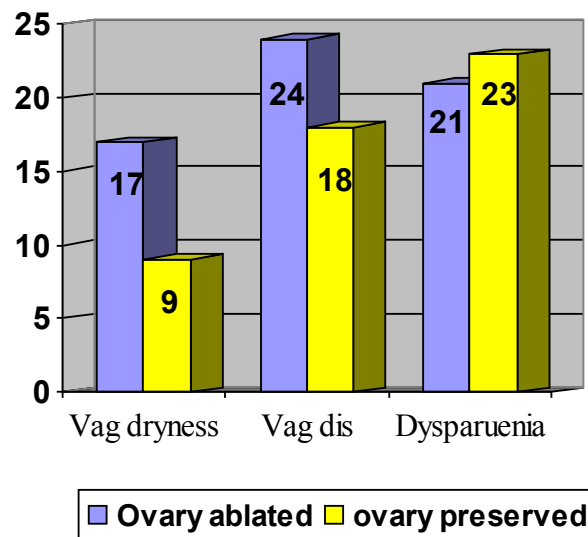


Figure 2. Sexual symptoms and ovarian ablation

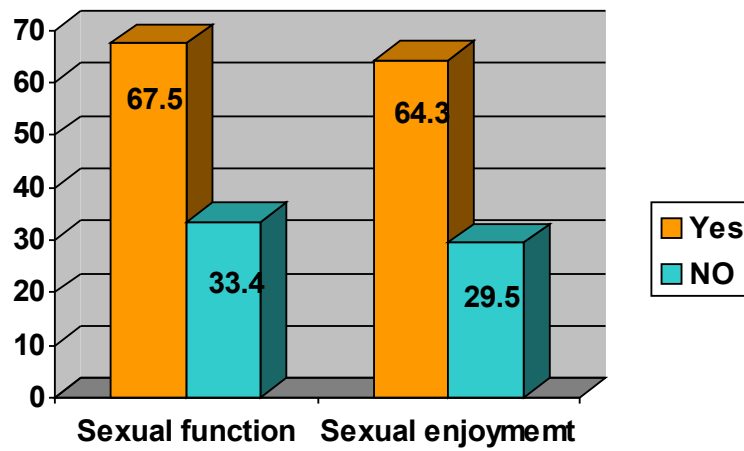


Figure 3. Hormonal Status and sexual function

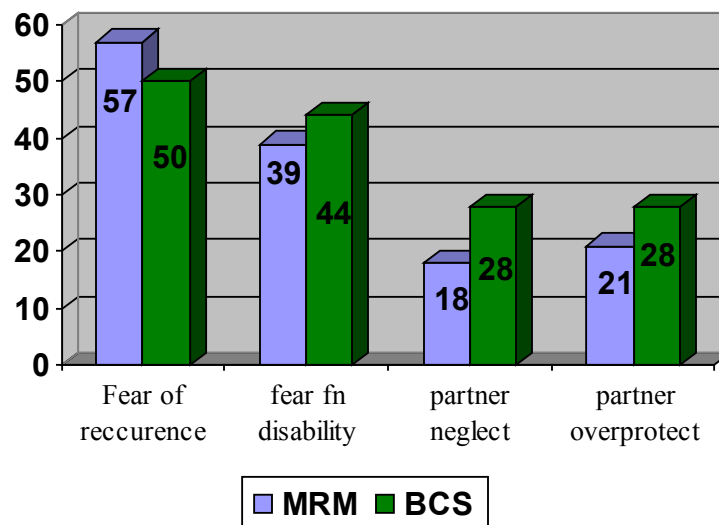


Figure 4. Fear and partner response to MRM and BCS

A total of 51 patients who attended the breast clinic and completed the questionnaire were taken up for the study.

The mean age at diagnosis was 30 years (21-35yrs) with 51% of the patients between the age group of 29 to 32 years. **(Table1)**

The mean age at the time of quality of life analysis was 35.1 years (23-47).

Demographic profile

Education status (Table 2)

27(52.9%) patients had completed primary education. Only 1 patient was a postgraduate. None of the patients in the study group was illiterate.

Occupation (Table3)

37(74.5%) patients were housewives at the time of diagnosis. 2 patients who were housewives at diagnosis took up a job as a labourer after the diagnosis of cancer. 1 labourer and the other a professional left their jobs and became house wives.

Marital status (Table4)

Of the 48 patients who were married, 2 got divorced and 2 of them became widows during the course of the treatment. Of the 5 who were single at diagnosis, 4 got

married and 1 continued to be single.

Family history of cancer was present in 6 patients (11.8%).

Stage and treatment (Table 5)

31 (60.8%) patients were in stage 2. Only 2 patients presented in stage 1. All patients underwent surgery with 35% of the patients receiving breast conservation surgery. Based on the protocol treatment at our institute all the patients received adjuvant chemotherapy and radiotherapy. 62.7% of the patients received CMF chemotherapy as per the institute protocol

Hormonal manipulation (Table 6)

Bilateral salpingo oophorectomy was done in 43.1 % of the patients, while radiocastration in 7.8% of the patients. 9 patients (17.6%) had chemotherapy induced amenorrhea of which 3 had permanent ovarian failure.

Receptor Status (Figure 1)

49% of the patients were receptor negative while in 29.4% of the patients the receptor status was unknown. Hormonal therapy was administered to 82.4% of the patients.

Menopausal status and child birth

22 (43.1%) patients had intact menstrual function of which only 2 patients had irregular cycle. Premature menopause was seen in 29 patients. Of the 9 patients with chemotherapy induced amenorrhea, 3 patients had permanent ovarian dysfunction.

3 patients had successful pregnancy after completion of therapy

The mean duration of follow up was 5.33 years (2yrs-17yrs).

Sexual and menopausal symptoms (Table 7)

Premature menopausal symptom was experienced in the form of hot flashes in 31.4 % of the patients. The common sexual symptoms were vaginal dryness (13.7%), vaginal discharge (21.6%) and Dyspareunia (21.6%). The sexual symptoms appeared to be higher in the ovary ablated group when compared to the ovary preserved group (figure 2).

Patients who had received hormonal therapy had a higher sexual function score and sexual enjoyment score than who did not which was statistically significant. (Table 8/ figure 3)

Quality of Life

The EORTC QLQ C30 and BR23 questionnaire was used for the assessment of the quality of life.

A high score for a functional scale represents a high /healthy level of functioning, a high score for the global health status/ QOL represents a high QOL, but a high score

for a symptom scale/item represents a high/ healthy level of symptomatology or problems.

The mean global health status score was 77.93. The functional scores of physical, role, emotional, cognitive, social and body image were high ranging from 80 to 89. The functional scores of sexual function, sexual enjoyment and future perspective were low in the range of 58 to 72. **(Table 9)**

The symptoms scales of fatigue, pain, insomnia, loss of appetite, breast and arm symptoms and systemic side effects were low in the range of 5 to 20. Only the financial score of the symptom scale was high with a score of 40.5. **(Table 10)**

Impact of MRM and BCS on quality of life

Functional scale (Table 11)

The functional scores of physical, role, emotional, cognitive and social were slightly higher or similar in both the mastectomy and breast conserving group and not statistically significant. The sexual functioning and sexual enjoyment were significantly better in the mastectomy group when compared to the breast conservation group. The scores for body image were also higher in the mastectomy group but were not statistically significant. Only the future perspective was higher in the BCS group

Symptom scale (Table 12)

The global health status was significantly better in the mastectomy group than the BCS group. The arm symptoms were also statistically significant in the breast conserving group. The financial problems were also more in the BCS group. The other symptom scales like fatigue and insomnia was similar in both the groups. Pain was found to be slightly higher for the BCS group.

The fear of recurrence was higher in the MRM group when compared to BCS group. The fear of functional disability was higher in the BCS group.

With respect to their partners, the percentages of patients with BCS had higher partner neglect (28%) and also were overprotected (28%) more than the MRM group. **(Figure 4.)**

Impact of Ovarian function on quality of life. (Table 13)

The sexual functioning and enjoyment were better in the ovary ablated group than the ovary preserved group and was statistically significant. The emotional, social, body image and future perspective appears to be better in the ovary preserved group though statistically not significant.

The overall global health status appears to be similar in both the groups.

Survival duration and Quality of life (Table 14)

The emotional and body image scores were slightly less in those with more than 6 years of follow up when compared to those with less than or equal to 5 years of follow up. The arm symptoms were also slightly higher in this group. The global quality of life and other functional and symptom scales were similar in both the groups.

DISCUSSION

The incidence of breast cancer in the age group 20-29yrs is less than 1% and 6.5% in the age groups 30-39yrs. The patients are in their reproductive age group and are concerned with fertility issues. Moreover there is a paucity of Indian data with respect to quality of life in this subgroup.

Impact of breast cancer on the demographic profile.

2 housewives had to take up a job as a result of financial difficulties following the diagnosis of cancer. 2 patients had to leave their jobs and they attributed it to partner's overprotection. With respect to marital status, 2 patients got divorced following the diagnosis of cancer. 4 of the 5 patients who were single got married after diagnosis.

The effect of breast cancer on the occupation and marital status did show some effect but the magnitude of the effect was not much as most of us would expect.

Kiebert et al have reported that marital and social relations appear to be unclear with 6 of the 11 studies reporting no difference and the other studies reporting differences that are inconsistent. [17]

Impact of treatment on quality of life

The study population constituted of young breast cancer patients who are long term survivors .The mean duration of follow up was 5.33 years. Our study concentrates on the quality of life issues in this subset.

The global health status and the functional scores of physical, role emotional , social cognitive and body image was comparable but the sexual functioning was lower compared to a study conducted in Indian women with breast cancer by Parmar et al. The arm and breast symptoms appear to be lower in our study when compared to the study by Parmar et al. [46]

1. Breast conservation and Mastectomy

It was surprising to note that the functional scores were better in the mastectomy group with sexual functioning and sexual enjoyment achieving statistical significance.

A review by Kiebert et al reported 4 studies with relation to psychological dimension in favor of the BCS group while there were 2 studies in favour of mastectomy. [17]

With respect to sexual function, of the 11 studies there was no difference between the groups in 7 studies while 4 other studies favoured the BCS group. But with increasing time this difference became less obvious. Our study again was in patients

with long term disease free survivors.

The global health status was higher in the mastectomy group. The arm symptoms and pain which was higher in the BCS group could be the reason for the lower quality of life in this group.

Breast conservation surgery did not improve the body image score. Of the 18 studies reviewed, 12 studies were in favour of breast conservation while the rest of the studies showed no difference.

The fear of recurrence appeared to be higher in the mastectomy group in our study. The reason could be that patients felt that mastectomy was done for advanced disease and hence the higher chance of relapse. This was investigated in 8 studies. In 6 of the studies no differences were found between the treatment options. Two studies favored the mastectomy group. [14, 47]

The financial constraints also appeared to be higher for the BCS group but did not achieve statistical significance. This could be attributed to length and costs of breast conserving treatment with the subsequent follow up and screening mammogram being higher in this group.

The impact of quality of life on the two treatment groups namely the breast conservation and mastectomy are gross categories that fail to distinguish the variety of procedures and the adjuvant treatment like chemotherapy, radiotherapy and hormonal

therapy.

There are several confounding factors

1. The reason for the overall quality of life being poorer in the BCS group is that the arm symptoms and the pain are not dependent on whether the breast is conserved or not. The arm symptom is dependent on the complication of the axillary dissection and radiotherapy to the axilla resulting in lymphedema. The pain may be related to the injury to nerves.
2. Stephanie in her study on sexual problems after surgery found that the sexual problems in younger women were not related to socio demographic factors or type of breast cancer surgery.[32] The reason for sexual functioning to be better in the mastectomy group could be dependent on the hormonal therapy. Forander et al have suggested that Tamoxifen prevents vaginal atrophy and improves sexual function [37].82.4% of our patients had received hormonal therapy. Our study also showed that patients with hormonal therapy with Tamoxifen had significantly higher sexual function when compared to those who did not receive Hence hormonal therapy could be a confounding factor.

The impact of BCT and MRM on QOL has shown contradictory results in different studies. A study by Janni et al [48] showed no difference was observed between the two groups in the QOL which was administered 46 months following primary treatment. In contrast Cohen et al found that women who had BCT experienced significantly greater psychological distress and marginally worse quality of life 40 months after surgery. [49]

2. Impact of quality of life on ovarian function.

The patients with ovarian ablation had slightly more vaginal dryness, vaginal discharge and dyspareunia than the ovary preserved group which was statistically not significant.

Bonnie et al in her review on breast cancer in young women- Effect on ovarian function, fertility and birth defects has described hot flashes, decreased libido, changes in sleep pattern, irritability, vaginal discharge and/or dryness and dyspareunia as common symptoms after ovarian ablation [50]

Though the patients with ovarian ablation had more sexual symptoms their sexual function and enjoyment was significantly better when compared to ovary preserved group. This could be explained by the hormone therapy which all the patients with ovarian ablation received.

The sexual function and enjoyment was lower in the ovary preserved group. Patients in the ovary preserved group had more patients with breast conservation with arm symptoms and hence affecting the overall quality of life including sexual function.

In our study chemotherapy induced amenorrhea was seen in 17.6% of the patients. 11.6% of the patients had temporary amenorrhea and 6% had permanent amenorrhea.

In the review by Bonnie et al, of the 128 patients, 59% continued to menstruate, 32% experienced temporary amenorrhea and 9% experienced permanent amenorrhea. [50]

The incidence of chemotherapy amenorrhea appears to be slightly less in our study.

3 patients had successful pregnancy following completion of surgery. The data on this subject is limited.

Survival duration and quality of life

The patients were divided into two groups .One group was with patients within 5 years after diagnosis and the other more than 5 years after diagnosis. Our study showed that the global quality of life and other functional scores were similar in both the groups. It is difficult to interpret because the initial scores at diagnosis are not available.

Limitations of the study

1. The initial quality of life scores in these long term survivors are not available for comparison
2. There are wide varieties of definitions of concepts and of applied assessment instruments for measuring the quality of life making it difficult for studies to be compared. Hence more studies in this subset of patients in the near future may throw some light.

CONCLUSION

- ✓ The effect of breast cancer on the occupation and marital status appears to be minimal.
- ✓ The overall quality of life with the exception of sexual function appears to be good.
- ✓ The quality of life and sexual function was marginally worse in the breast conserved group when compared to mastectomy.
- ✓ Adjuvant hormonal therapy with Tamoxifen significantly improved sexual symptoms.
- ✓ Preparing younger women for the impact of breast cancer and helping them deal with problems may improve their quality of life.
- ✓ Younger breast cancer survivors may be in need of interventions that specifically target these issues like non systemic products to alleviate vaginal dryness and also programs to help women deal with body image concerns.

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PROFORMA

Clinical Index No. : Out Patient No. :
Age at diagnosis : Name & Address :
Current Age :
Sex : Phone No :
Occupation
 Past :
 Present :
Education :
Stage :
Date of admission :
Treatment
 Surgery : Yes / No IF Yes : MRM / BCS
 Chemotherapy : Yes / No IF Yes : CMF / FAC
 Radiotherapy : Yes / No
 Hormone therapy : Yes / No Receptor status : ER / PR / UNKNOWN
 BSO : Yes / No
 Radiocastration : Yes / No
History of cancer in the family : Yes / No
Menstrual History
 Menstruation : Yes / No
 Cycles

- No . of days :
- Regular / Irregular
- Menorrhagia / Oligomenorhea

Contraception : Yes / No IF Yes - Type :

Premature Menopause leading to loss of Fertility : Yes / No

Chemotherapy induced Amenorrhea : Yes / No

Marital status at Diagnosis : Single / Married / Divorced / Widowed

Current Marital status : Single / Married / Divorced / Widowed

No. of children : Supported by :

Childbirth after Treatment : Yes / No IF Yes, How Many :

Any Abortions : Yes / No IF Yes, How Many :

Do you have fear for recurrence.y/n

Do you have fear of functional disability y/n

Are you neglected by your partner y/n

Does your partner over protect you? y/n.

Do you have hot flashes? y/n

Do you have vaginal dryness? y/n

Do you have vaginal discharge ? y/n

Do you have pain during sexual intercourse ? y/n

Date of Interview :

Interviewer's Signature : Time taken: